

# **The Bioethics Discussion Forum - An Implementation of an Internet-Based Bioethics Information Analysis Resource**

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*Ethical analysis is crucial to decision making in biomedicine and health care, necessitating both rapid access to diffusely disseminated sources of information pertinent to bioethics and promotion of analysis in the field of bioethics through a resource for information analysis. We developed the Bioethics Discussion Forum, an Internet-based information analysis resource, in order to supplement the Bioethics Online Service with an interactive information medium to meet the demand for such an interactive resource.*

*The Bioethics Discussion Forum has shown promise for information analysis, providing an arena for the review and discussion of complex bioethical information, establishing a connection nationally and internationally among individuals with high levels of expertise in bioethics, and providing a template for future interactive informatics services.*

## **PURPOSE**

The next several years will bring significant changes in American health care and the way it is provided to persons of different ages, gender, socioeconomic status, and geographic locations. Ethical analysis is crucial to the evolution of these changes; and access to scientific, economic, legal, philosophical, and health policy information is crucial to ethical analysis.

Institutional ethics committees, ethics consultants, primary care physicians, health care institutional administrators, health care legal counsel, and students in the health care field need to obtain information about bioethical issues quickly and accurately and to analyze and discuss these issues. Additionally, there is an increasing interest on the part of the public to learn about and participate in the discussion of issues in bioethics.

In initial response to these demands, we developed the Bioethics Online Service as an outreach of the Center for the Study of Bioethics at the Medical College of Wisconsin (MCW) to provide this access and to provide a forum for discussion of bioethical issues (Derse & Krogull, 1994). This gopher-based

service, which allows Internet access and now enjoys widespread Internet use -- with over 25,000 users from over 42 countries logged in the first 2 years -- has shown promise in utility and ease of access, and has been used as the template for other informatics developments on our campus and beyond. It has also been chosen by America Online as one of its featured Internet health-related databases.

However, despite this initial success, the Bioethics Online Service was used primarily as an information repository without the capability for interaction or analysis of the data provided. Our users expressed a desire for a forum for the analysis and discussion of the information provided through the Bioethics Online Service and elsewhere. In response to these demands, we developed the Bioethics Discussion Forum, which has since been integrated into the Bioethics Online Service.

The following purposes were identified for the establishment of the Bioethics Discussion Forum:

1. Analysis and development of the knowledge base in the field of bioethics through promotion of a high level of discussion among leaders in the field of bioethics.

The field of bioethics is rapidly burgeoning in its development. The issues, which involve the interface of medicine, law and ethics, are often current and featured in the academic and lay press and other media. Many of our users -- a mix of academics, ethics committee members and ethics consultants, and others with interests in bioethics -- had expressed satisfaction with the Bioethics Online Service as an information repository, but also expressed a desire for a means to engage in contemporaneous information analysis through discussions in a less formal environment, with a rapid response to contemporary topics and an ability to engage in point-counterpoint types of discussions. One goal was to develop a forum which would foster a high level of professionalism in this kind of discussion.

2. Integration of the forum for discussion into the existing structure and constraints of the Bioethics Online Service.

The Bioethics Online Service was developed as an information resource, with a repository of abstracts and journal articles, news accounts, and other information sources with a high degree of reliability of information. The planned Bioethics Discussion Forum needed to be integrated into the existing philosophy and structure of the Bioethics Online Service.

Conversely, the Bioethics Online Service's popularity as an outreach resource could be used as an entree to garner interested and qualified individuals for the Discussion Forum.

3. Use of the Discussion Forum as an academic resource for the Medical College of Wisconsin and for other academic institutions.

The Medical College of Wisconsin, as sponsor of the Bioethics Online Service and the Bioethics Discussion Forum, has an interest in maintaining a high level of professionalism and rigor in the academic discussion taking place on the Forum. Additionally, the graduate program in bioethics at MCW, which educates masters students in bioethics, wishes to encourage its graduate students to be exposed to a high level of discourse on issues of bioethics, in their quest for professionalization. As well, other academic bioethics programs and their graduate students may benefit from such a high level of discussion.

4. Use of the Discussion Forum as an IAIMS/outreach resource.

As a current Phase I Grant awardee in the National Library of Medicine's Integrated Advanced Information Management Systems (IAIMS) program, these Bioethics services serve as a template and planning guide for the goal-oriented design, development, and implementation of numerous other internet-based initiatives at MCW. Mechanisms need to be built in to the Discussion Forum enabling the service directors at MCW to receive constant feedback about the usefulness of the service and its content. This may occur through the level of discussion, numbers of new topics and associated responses, and levels of service subscriptions versus terminations. Monitoring this data will provide valuable information for the

continued improvement of all components of the Bioethics Online Service and will also provide data for the redesign or discontinuation of services that no longer meet user needs.

5. Encouragement of professionals to use the Internet and e-mail to increase professional communication.

In the development of the Discussion Forum, one goal was the encouragement, for those whose professional activities encompass bioethics, to become familiar with the Internet and e-mail. This is important for increasing the timeliness of professional communications regarding contemporary issues. Our experience with the Bioethics Online Service had demonstrated the Internet as a way to facilitate the rapid dissemination of bioethics information. The Internet was also seen as a way to facilitate the development of the profession itself through timeliness and rapidity of information and analysis.

6. Optimal utilization of existing hardware, software and information technology systems personnel resources.

Because of existing hardware, previous software choices, and limited financial and information technology personnel resources, our goal was to obtain as wide a forum as possible with the lowest reasonable monetary investment. Because we planned to offer the Bioethics Discussion Forum (as well as the Bioethics Online Service) without charge to the user, we needed to keep our financial investment as minimal as reasonably possible.

## METHODS

### Technology

The Medical College's Office of Research, Technology, and Information has successfully partnered with the Bioethics Center to implement the Bioethics Online Service through MCW's Medical Information Network (MIN). This internal network is tied to Wiscnet for state-wide communications, the Internet for national and international access, and services such as America Online. This configuration offers points of access for faculty, staff, students, other professionals and lay public. Thus, the Bioethics Online Service can be accessed by anyone with a computer, a communications program, and a modem from almost any location.

In the course of developing this service, several internal and external database and information management programs were evaluated. Gopher emerged as the system of choice to facilitate access from multiple routes, provide a highly structured (menu-based) method for information organization and retrieval, and implementation costs were minimal using existing computer and staff resources. Usually, Gopher requires that the user have "client" software running on their personal computer. However, MCW's telnet and dial-in connection system provides a Gopher client as part of a menu choice to connect to the Bioethics Online Service.

Because of the demand for an interactive discussion service through which subscribers could exchange ideas and information, we sought to provide online interactive functions including public posting and archiving of information. We found that the technical implementation of the Gopher interface does not support these functions without linking traditional bulletin board software (BBS) to the Bioethics Online Service.

The few available UNIX versions of bulletin board software that were reviewed were felt not to have an appropriate interface for the Bioethics Online Service. Other (PC and Macintosh) BBS software packages were considered, but these required additional separate systems. All of these systems require significant input and organization from system operators or discussion group moderators, which would add significant burdens to our limited human and financial resources.

Therefore, we turned to an automatic mailing list processor, Listproc, to address these needs. This list processor is low in cost as shareware, supports automatic enrollment of users, distribution of current and subsequent commentary, and links to existing Gopher-based services. This link allows the list processor to be mirrored to a local campus bioethics news group and the main Gopher-based Bioethics Online Service. Thus, Gopher serves as a permanent, read-only archive sorted in reverse chronological order, while the mirrored list processor and news group allow for on-going discussion among participants using either service. We also developed a link to a World Wide Web page as an additional read-only site with hypertext searching capabilities.

Disadvantages of implementing the list processor on our Unix platform include the necessity of staff to master the basics of Unix and the list processor

command syntax, lack of software user support, and the necessity of the prospective subscriber to send text commands in a prescribed order to subscribe, to "unsubscribe", and to perform other functions, such as compiling a digest of daily postings or searching the archive.

However, the low cost of development and maintenance has allowed the Medical College to offer the Bioethics Discussion Forum and the other offerings of the Bioethics Online Service on the Internet free of cost to the user, which has, in turn, allowed a wider audience than might otherwise be available.

### **Access and Recruitment**

Initially, individuals who had expressed an interest in the development of the Discussion Forum were contacted and recruited as participants. Information about how to subscribe to the discussion forum mailing group was posted on the Bioethics Online Service (and consequently on America Online, because of its gopher links to the Bioethics Online Service). Flyers were distributed at national bioethics professional meetings. Other contacts included word-of-mouth recommendations. New members of the discussion forum received a compilation of the previous week of discussion, so that new members would be able to follow the current topics from the beginning.

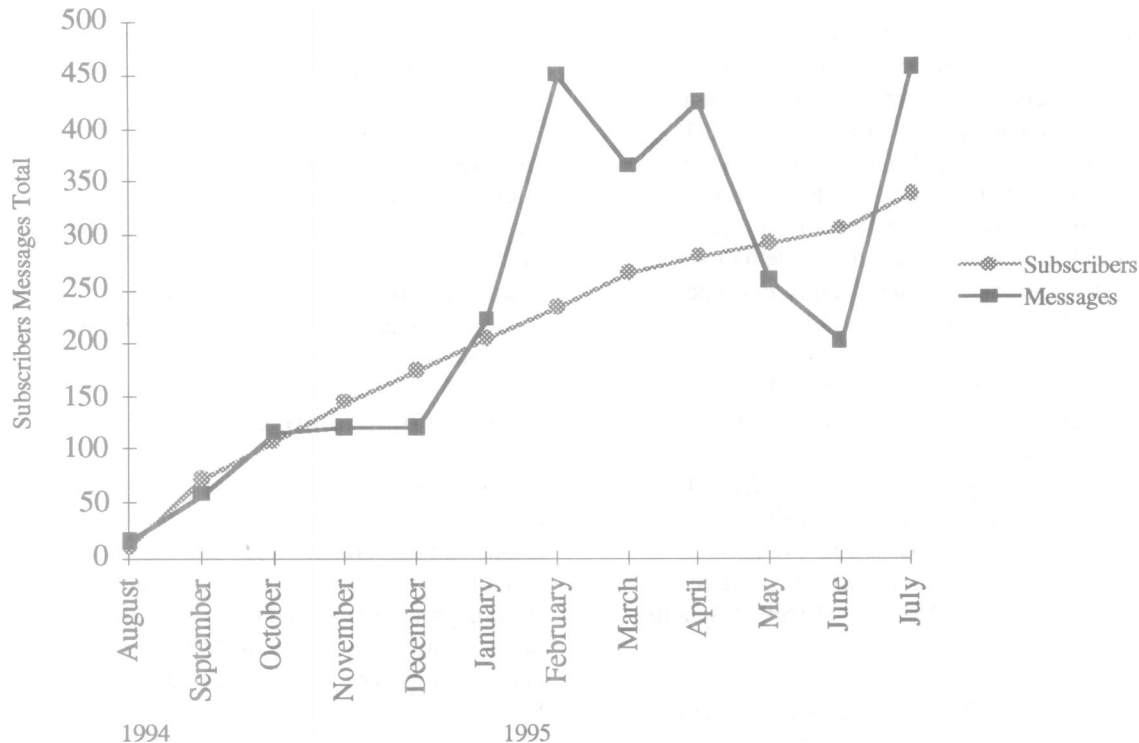
### **Service**

Because of personnel and time limitations, help is offered mainly through e-mail with the individual or a site administrator. Help is also available by telephone. Most of the questions received by support staff concern means of access to the Bioethics Discussion Forum. Some of the most problems identified are site specific, concerning e-mail software configuration and use. User addressing problems are also common.

## **RESULTS**

The inauguration of the Bioethics Discussion Forum waited until a critical mass of 12 individuals were recruited. On August 23, 1994, the first question concerning a timely legal case in bioethics reported in the national media that week was posted on the forum, and the first discussion began. The Discussion Forum has not been silent since.

### Bioethics Discussion Forum Usage



Since its inauguration, the Forum has been featured in news and journal articles, faculty presentations, and papers. In the first 11 months of operation, membership increased from 12 to 340 participants from 9 countries; requests for new memberships averaged 48 per month; the average number of messages per day went from 1.25 to 7.88; the number of conversation threads (simultaneous topics) under discussion at any one time averaged 2.5; the average number of messages per month per user is 1.11 and the amount of staff time to provide technical and systems support averaged 2.0 hrs/wk. It is important to note that we met our objectives for the service to show significant increases in participation with minimal technical resources (and cost).

Interestingly, a number of legal and ethical issues have been identified by participants about the service itself, which include:

1. The need to offer the ability to discuss actual bioethics cases on-line. To accomplish this requires increasing security and confidentiality awareness among users, emphasizing the importance of excluding identifying information when submitting cases for discussion.

2. Intellectual property issues of copyright, ownership of ideas, appropriate use of ideas developed online, necessity of permission in citation of ideas and proper format for citation need to be clearly defined.
3. Evolution of the membership in the Discussion Forum and other Bioethics Online Service offerings needs to be continually analyzed and defined - unrestricted (including the general public, the press, government officials) versus restrictions of some kind based on various criteria (e.g. expertise, professional credentials, or academic affiliation).

This Forum has established itself in a unique way in that it is meeting a clear need by an international community. The Forum has attracted a diverse, credible, and contributing group of national and international participants. More importantly, the discussion and activities taking place through the Forum have been sufficient to retain these individuals and to encourage their continued membership and active participation.

## **FUTURE DEVELOPMENTS**

Topics discussed on the Forum have increased at a heated pace. A number of topic threads may be discussed in any given day's accumulation of topics. The list processing software does not have the capability to split off topics, and the same restrictions of personnel and finances restrict the movement to a true bulletin board interface.

The majority of participants are either academic bioethicists or other professionals whose activities encompass bioethics. A certain number of individuals have expressed a preference for a forum devoted strictly to the discussion of cases and problems faced by ethics committees and ethics consultants. Plans are now being made for a specific forum to address just these topics.

We hope also to have a Web-based service with true thread-oriented discussion paths in the next few months. Finally, we hope to keep the service free to users by keeping operating costs minimal.

## **CONCLUSION**

Through the Bioethics Discussion Forum, the Center for the Study of Bioethics at the Medical College of Wisconsin will help facilitate analysis and discussion of bioethics issues by national, and international audiences of those whose professional interests encompass bioethics as they confront the ethical challenges posed by continued scientific advances.

As a result of our endeavors, other educational institutions and professional entities have expressed plans to develop similar resources based on the template of the Bioethics Discussion Forum. We applaud these efforts and look forward to the development of equivalent services worldwide.

## **References**

1. Derse AR and Krogull SR. The Bioethics Online Service - An Implementation of a Bioethics Database and Information Resource. Proceedings of the 18th Annual Symposium on Computer Applications in Medical Care, Washington D.C., November, 1994, pp. 354-357.

## **Acknowledgment**

The authors wish to acknowledge the contributions of these individuals in the development and implementation of the Bioethics Discussion Forum (BDF): Mary Bess Zollo, B.S.N., Coordinator BDF; Carl Weigle, M.D., listowner of PICU (an Internet discussion forum for pediatric intensivists).